National Osteoporosis Society: 25 years of making a difference

A fragility fracture is often the first sign that someone has osteoporosis, as there are no associated signs or symptoms, and this has lead to the condition being called the "silent epidemic." For the past 25 years, the National Osteoporosis Society have been anything but silent about osteoporosis. The charity's CEO Claire Severgnini talks to Dawn Powell about the past, present and future management of osteoporosis.

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Twenty-five years ago, in 1986, neither the general public nor healthcare professionals knew much about osteoporosis. Few doctors associated the condition with an increased risk of fracture, many believing that it "just" caused kyphosis of the spine or "dowager's hump" in elderly women.

The lack of awareness of osteoporosis prompted Dr Allan Dixon and Commander Dickie Rowe to set up the National Osteoporosis Society (NOS) to increase awareness and improve the management of the condition. Now, 25 years later, thanks in no small part to the work of the NOS, osteoporosis is firmly on the radar of both healthcare professionals and the general public.

The charity's CEO, Claire Severgnini, says that there have been several "milestone" achievements for the NOS. "Our first major television appearance in 1992 was a huge step forward in raising awareness as 10 million tuned into TV-am to hear discussions about the impact of osteoporosis and preventative measures." She adds that seeing the first government strategy on osteoporosis, after years of lobbying, six years later in 1998 was also a "great success".

A massive disappointment for the NOS has been that osteoporosis, so far, has not been included in the quality and outcomes framework (QOF). It came close to being added to the framework in 2008 but a change in GPs' working hours lead to it being rejected. "However, we didn't give up. After years of campaigning, osteoporosis has finally moved a step closer to being given the recognition that it deserves. It has now reached a crucial stage in the bid to be included in the QOF. There has been a committee meeting to decide which health conditions will be moved on to the final stage." The final decision will come later this year.

Management

A quarter of a century is, of course, a long time in medicine and much has changed in the management of osteoporosis since the NOS first started.

Today, a dual energy X-ray absorptiometry (DXA) scan is seen as the goldstandard method for measuring bone-mineral density and diagnosing osteoporosis. While many osteoporosis specialists argue that we over rely on DXA scans and that access in some areas is poor, the situation is immeasurably better than it was 25 years ago. Mrs Severgnini says: "For patients with osteoporosis, getting a diagnosis was a very difficult process. DXA scanners were not yet available on the NHS and were only being used for research purposes."

Like DXA scans, bisphosphonates were not available in 1986. The only treatment for osteoporosis was hormone replacement therapy or calcium with vitamin D. "There was no national guidance on the use of available treatments for osteoporosis and there were no national campaigns that aimed to ensure that patients across the UK were given access to the most effective treatments."

Now, a variety of effective treatments are available on the NHS. Studies show that they

reduce the risk of overall fractures by up to 50% and the risk of vertebral fractures by up to 70%.

Although we do now have NICE guidance for managing osteoporosis, it is controversial. The NOS have been very vocal about the fact they think the current NICE technical appraisals are "unethical" and "unworkable." Mrs Severgnini explains: "We have been working closely with NICE to make positive steps towards more appropriate guidance. The current guidance focuses only on postmenopausal women so large groups of people with fragile bones are missing out on treatment. The current production of a short clinical guideline on fracture risk assessment is just the starting point to changing this."

Several osteoporosis experts also believed that the NICE guidance was not adequate and collaborated to form the National Osteoporosis Guideline Group (NOGG) and produce their own recommendations. The NOS overall support the NOGG recommendations, but they are still working with NICE to ensure that improved guidance will be available that will cover both the management and treatment of osteoporosis for all. "In the meantime, we urge clinicians to use their discretion, as recommended by NICE themselves, to treat people at risk of fractures effectively and appropriately."

However even if NICE does produce guidance that NOS agree with, it may not be implemented. Back in April, the NOS reported that some Trusts were denying patients access to denosumab (Prolia) on the grounds it was too expensive despite NICE guidance recommending it. Mrs Severgnini says the NOS are concerned by this finding. "Denosumab has undergone a great deal of analysis by government regulators who look at the effectiveness of the treatment and the cost. The drug should be available to people with osteoporosis who meet certain criteria, such as inability to take other treatments, previous fracture or very low bone density measurements. Using it as guidance suggests is proven to be cost effective. "

She adds that Trusts that block the drug on the grounds of costs alone are not seeing the "bigger picture". "Hip fractures cost the UK £2 billion in health and social care costs every year. Upfront costs of treatment need to be considered alongside long-term benefits. If we can prevent fractures, we can save money and improve people's lives."

A recent report by the Royal College of Physicians indicated that patients are also being denied access to certain services as well as pharmacological treatments. According to this report, only 38% of health services provide any kind of fracture liaison service. In the eyes of the NOS, such services are essential to preventing future fractures. "Fracture liaison services are internationally recognised as the most effective way of preventing broken bones in older people." Mrs Severgnini adds that a coordinated fracture prevention service prevents people from "slipping through the net." The Department of Health estimate that fracture liaison services could save the NHS £8·5 million over a five-year period.

The future

The "future of the NHS" is a topic that has barely been out of the national and medical press since the coalition Government announced its plans to radically shake-up the structure of the NHS last year. Like many healthcare professionals, the NOS were concerned about how a new structure would affect the management of osteoporosis. "GPs need to play a pivotal role in the prevention, diagnosis, treatment and care of patients who are at risk of broken bones. While it is good for GPs to have a greater involvement in the commissioning of NHS services, the design process for a successful local fracture prevention service needs input from a range of professionals." Therefore, the NOS welcomes David Cameron's recent announcement that other healthcare professionals, as well as GPs, will be involved in the commissioning of services. Mrs Severgnini says that the new revisions are "in line" with their hopes.

A major element of the NOS's work is funding research into the management of osteoporosis, with as many as 14 projects receiving money from the NOS in one year. Their current projects include researching environmental and psychosocial concomitants of falls, injury prevention in institutional settings, and a genome wide analysis of gene-nutrition interaction in osteoporosis. "We also have a number of studies looking at osteoporosis in men, including a detailed look at distal forearm fractures in men and research into bone density, geometry, and muscle function in men aged 40 to 80 years and their relation to sex hormones."

One particular project is a novel primary care based, case-finding strategy for vertebral fractures, which the NOS hope will lead to more vertebral fractures being

identified. "Vertebral fractures are seriously under diagnosed, which leaves people suffering great pain without knowing the cause."

In terms of the next clinical breakthrough, Mrs Severgnini believes that, realistically, it will be bone turnover markers. "In a clinical setting, they could be used to monitor response to therapy or more effectively target treatment."

For the NOS, the ultimate goal is to make sure that a wide range of treatments that are effective at preventing fractures are available. "Osteoporosis is still not fully understood so more research is needed before we can predict any major changes to the way it is treated. Ultimately, though, we want to see an end to preventable fragility fractures...we will continue to do everything in our power to achieve this."

All facts and figures mentioned in this article can be found on www.nos.org.uk. This website also has more information on osteoporosis and the work of the NOS, including its next professional conference (1–4 July 2012 at Manchester Central Convention Complex).